

OUR VOICE

The Newsletter of Autism Network International

New address for ANI:

Autism Network International
P.O. Box 448
Syracuse, NY 13210-0448

Neat things about our new address (contributed by James Sternberg, James Bordner, Avi Blackmore, and Jim Sinclair)

The digits of 448 add up to a number it's divisible by.

The progression of 2, 4, 8, 16, 32, and 64 (all of which 448 is divisible by) looks very neat when written in binary:

10
 100
 1000
 10000
 100000
 1000000.

448 is 700 base 8.

448 is divisible by 2, 4, 8, 16, 32, AND 64.

448 was the combination of the first bike lock Jim Sinclair got at age 8.

448 contains James Bordner's favorite number: 44.

448 is divisible by 7, which is the number of letters in James Bordner's last name.

448 is an anagram of the square of Jim Sinclair's favorite number: 22.

REMEMBER OUR NEW ADDRESS!

LIFE SINCE TORONTO AND WHAT I HAVE BEEN DOING by Jean-Paul Bovee

To those of you who know me and for people who do not, my name is Jean-Paul Bovee and I am a graduate student working on his master's degree in Library and Informational Science at the University of Missouri. I am autistic as well, being diagnosed as such at age two and a half. I am now 25 years old and have been going to universities for a while. Now you have an introduction of who I am.

Why am I starting out with Toronto as my beginning? Toronto was the site of the 1993 International Autism Conference and was important for me in many ways. I got to be reunited with people that I do not see often such as Jim Sinclair, Kathy Lissner, and other wonderful people who have dealt with many similar things as myself, and a lot of different things as well. I also got to meet wonderful people like Katherine French whom I can be a friend and share many things with. It was an experience and it really was the start of the new things that would be going on in my life.

Last September I started a new and wonderful job with the Central Missouri Regional Center in Columbia, Missouri. I am the Autism consultant with the center. I work with wonderful people, who make me feel special and who value what I do. I am there to observe and suggest ways to work with the individuals that we work with. I can be an advocate for persons with Autism as well as for persons with other conditions. I have been working with case managers, training persons, and our regional center specialist and director as well. It is a rewarding job that will end too soon. I will be done at the end of June and will be taking my comprehensive examinations for my degree in July.

Other than that, the rest of 1993 was life as usual. I am like any other

student. I study, take my tests, do fun things with my friends, and so on. I have many friends both with Autism and without.

I will now talk about the National Autism Symposium. It was March 4 and 5 at St. Louis. I arrived there the Thursday before the conference and stayed at the hotel. On Friday, I went to some of the meetings and met with my friends at the ANI booth. That was the main highlight of the convention to me. I wanted to spend time with people that understand me and I never have to explain what I have to deal with. It can get frustrating out in this world dealing with people. I feel that I always have to change to satisfy them, but they are not going to change so that I can be accepted. I do well in my life and my dealings with people, but it has all been work on my part. Why can't persons who do not have a condition change to accept me?

I spent wonderful time there not only with ANI friends, but also with friends from my work. It was nice to hang out with them at non-work functions. They are so neat and feel that they are learning a lot from me. I guess that I have a lot to say.

After the conference, Katherine F. came out to visit me in Columbia. We got to visit and spend some wonderful time talking and getting to know each other a little more in person, than just on the phone. For those of you who do not know her, I advise that you get to. She is a wonderful person, whom I have the pleasure to call my friend. However, I have the pleasure of calling each person that I know personally in ANI my friend, because I can be myself and do what I do when I am with you. It means a lot to me.

Now after all of this, I have a

few things left to say. In this world, I guess I thought that I did not have too much to say. I do what I do, accomplish what my goals are, and plan to make it living in this world with my work and my abilities. That does not sound that exciting, but that has been what I have been aiming for my entire

life. I want to be able to have people think of me as Jean-Paul and not some nameless person with Autism. Being Autistic is not a concern or worry for me, but it is something to feel good about and feel proud about. I am Jean-Paul and I am Autistic and I am very proud of it! You know who I am.

The Eclipse of the Moon

I looked out of my bedroom window.
I saw the moon obscured by the earth's shadow.
As I watched more and more, gradually more of the moon appeared,
Till I saw there was a full moon in the sky.

The world was in tune to the light of the moon,
And the moonlight faded in the eclipse of the moon.

I looked out at the sky.
I wondered what secrets were hid from the earth as the moon was eclipsed.
The moon must hold a lot of secrets about the earth.
The moon has been looking down at the earth for a very long time.

My mind was in tune to the light of the moon,
And the moonlight faded in the eclipse of the moon.

It was very soothing to see the full moon appearing again in the sky.
This only happened three days before Halloween.
It was a kind of mystical happening for me
Although most of the people I spoke to the next day never saw it happen.

The sky was in tune to the light of the moon,
And the moonlight faded in the eclipse of the moon.

26th October 1985

David Miedzianik

ON THE TRAIN TO INDY
by Kathy Lissner-Grant

As a child nobody ever sang a song to me for comfort or before I went to bed. I never had that until July 1991 when my autistic friend, Barbara Moran, sang to me. One of the songs she sang was "City of New Orleans, I'm Your Native Son." She sang that song and others when we were on the train going to Indianapolis for the ASA Conference. Every time she sang the "New Orleans" song, I wanted her to sing it again and again. I loved to hear her sing. She has such a lovely and calming singing voice. I just loved it when this brown haired lady with a little bit of gray sang. I felt as if she was a mother singing to me.

Every time I hear this song, I

cry because of the memory of sitting on the train hearing my dear friend sing. I remember a few months later at the VP Fair in front of the Arch, Willie Nelson sang this song. I cried because I thought of Barbara. This woman did something special for me. She did what no other woman in my family did for me, and that was sing.

What better song can someone sing on the train from St. Louis to Indianapolis than a song about being on a train to another city? I know that this is one of the songs that will be played at my wedding. This is the only song I associate with a person I know. And that is a lot. Thanks, Barbara, for this treasure!

Life in the deep is quick as
sand, passing through time
as we know it, not as it
was, was meant to be, not
be, but to die is the ultimate
end and to live such death
is the greatest beginning,
the start of a new end
the birth of the Phoenix,
oh ethereal bird, take me
to paradise, sing me a
traveling song, teach me
a new road, live in me
that I might feel your flame,
byrne my desire, own my life.
You should be like us, feeling like
we do, like you love to... in eternity

Iatia

Hi Jim —

Jeff has been writing a lot lately and has come up with some terrific stories. I hope you can use them in OUR VOICE. May I ask a favor? If you are going to print his stories, Jeff would be thrilled to get a note from you letting him know his manuscript has been accepted for

publication. His classmates and teachers would also be thrilled; the core of their language arts curriculum is "Writing and Publishing Workshop". The teachers "publish" a single copy of each child's work for the classroom library, but as far as I know, no one in Jeff's class has yet been published outside of the school.

Jean Hunter

The Day I Got Sick at the Sciencenter

3/17 (St. Patrick's Day)

By Jeffrey

On August 24, 1993. A Tuesday. Dad took me to school. Amy said, "We're going to the sciencenter! a fun place!" The Sciencenter! I said. I think I feel sick!

So they took a bus to the Sciencenter.

First we played. We went out to the Playground. And I got sick.

When Michael took me in I still got sick. I threw up by the women's and the men's bathroom and by the water fountain. Two of the sciencenter people rushed me to the women's bathroom. A little girl went to the bathroom when I was sick. her name was Isha. Debbie and Amy went to me. Debbie said, "Please wait for Dad." So I waited And Waited. They called Dad. Finally my Dad got here. I got my lunch, a new shirt and we drove all the way home. I watched constipation.

The End.

Sledding At Strawberry Hill with Larry

By Ted and Jeffrey 3/24/94

We went to strawberry hill with Larry. We went on the hill and got on my orange sled with Larry. Mom got me and Larry a great big push. But — something happened!

There were three huge bumps at the middle. Didn't see them of course!

I went over the first one and the second. The first one and the second one were okay. But —

When I hit the third one, I flew four feet in the air and landed on my body and hurt it.

Mom came to get me. But Larry was still on the sled. He didn't fall off or anything. He had reached to the bottom. Mom made a slow track to go on.

THE END

ABOUT "FIGHTING AUTISM"
by Donna Williams

About that section in *Somebody Somewhere*. Originally it had a heading: "What autism is to me." This was dropped by the editors but is getting reincluded. About it being against the feeling of the whole book, no it is not. Nor is it against autism. Perhaps I can sum some of this up.

THE DEFINITION:

For me there is Simply Be (a system of relating open equally to auties as non-auties but easier and more natural for auties), "The World" (said Three World) (a different system of relating open equally to auties as non-auties but easier and more natural for non-auties), the world (said the world) (the natural-physical world), My World (a system of perceiving), and Autism. I am all for Simply Be. I am tolerant and at times accepting of "The World" where it accommodates me. I can't help My World and I live with that and sometimes cherish parts of it (though not the whole because some parts are bad). The world (the natural-physical world) can be beautiful and I find belonging in it. Autism is sometimes my sanctuary and sometimes my prison. When it imprisons me, I am at war with it.

Autism is divided into two parts for me—body (brain) and spirit (mind) and both can have good and bad sides. I am at war with the war waged by my autistic body (brain) against my autistic spirit (mind). That means I am, in effect, often at war with my autism.

MY STANCE:

I don't want to attack anyone's views. I try to respect them. But for me, there is never just one way to view autism. All things have their good and bad side. Autism too. AUTISM'S BAD SIDE is not just to do with how "the

world" compounds autistic difficulties, nor how auties hate and hurt in trying to be "the worlders'" version of "normal" or "a success." Autism's bad side is also inherent. As inherent as its good side. It is this inherent bad part that I am at war with because it is at war with my spirit. I am not at war with autism's good side as it is not at war with my spirit.

I have met many auties—able and less able—who don't fight their autism. Some don't fight because they used to but gave up. Some fought on the side of "the world" for the wrong things but saw through all the acting normal bullshit. Some never perceived any inner battle so weren't driven to fight.

I think it is the nature or destiny of some auties to accept their autism. These are the ones who sense no overwhelming contradictions between their autistic spirit and their autistic brain. They do not feel overwhelmingly suffocated within. I am not suffocated all the time. My autism is my sanctuary and my prison. I fight the prison part when it suffocates me.

It is the nature or destiny of others to fight the walls of their autism. *Some do this for the wrong reasons*—to be something they have been taught they "should be" or "could be" but for which they have no true want, only blind compulsion. There are others, able and less able, who DO NOT HAVE A NON-AUTISTIC PERSON INSIDE but do have driving spiritual-emotional (not theoretical-mental) wants, likes, interests, desires to share and express that ARE overwhelmingly suffocated by the misfirings of a physical autistic brain (not to be confused with an autistic mind).

When many RFAs talk of how auties should accept their autism and NOT fight it, they are talking of the imposition of "the world" in trying to mold the "appearance" of autism and even its "beingness." I call this the "proud to be an autie" stance. I think this stance is right. Many "the

worlders" arrogantly assume the value of their system of relating based upon their seemingly unquestionable ideologies of how to relate, think, feel, experience. Some are so nazi that they want more than conformity, they want to eradicate the autism beyond the surface conformity—like woodworm digging deeper and deeper. I AM against THIS. I stand firm on my right to be who and what I am and to not be recklessly contorted by fools who have never and can never walk in my shoes. BUT, this is something TOTALLY different to what I am talking about when I say I WILL FIGHT MY AUTISM.

WHY AND HOW I FIGHT AUTISM AND WHAT I AM FIGHTING:

When I say I will fight my autism, I mean that if there are tinted lenses that will change my perception from 2D to 3D I will wear them. If they will put the disjointed bits without context together as a joined-together whole picture that I can take in at one look with a feeling of being part of that picture instead of external, then I WILL WEAR THESE IF THEY MAKE ME FEEL SAFER AND FEEL LIKE I HAVE MORE BELONGING IN MY VISUAL WORLD AND HAVE MORE PROCESSING TIME BECAUSE I'M NOT MENTALLY GLUING EVERYTHING TOGETHER IN MY HEAD AND SPENDING ALL MY TIME MAPPING. Perceptual problems have nothing to do with my (autistic) spirit. They have to do with my brain—a part of my body.

When I have a want to look at or listen to or be with something/someone/somewhere but my autism makes it sensorily painful to do so then I will use tinted glasses, ear plugs, a heavy coat and the ability to ask for my environment to adapt to my needs so I can have my want. By doing this, I am at war with my autism and I do not confuse the not-want of a physical-brain sensory response with my own (autistic) spiritual (mind) life-want.

When I feel overwhelming emotional closeness to someone and have a burning urge to blossom like a flower in my expression of these feelings, then I will fight my autism for my

ability to stay and not run. When my brain misinterprets the body messages of excitement as anxiety and fires all the messages to run when it is my heart's want to stay, I will fight this brain-misfire caused by autism.

When I watch my friend through a window doing something and in my mind I imagine being there and sharing in what they are doing and my heart gets happy with the thought and drives the action-want to join that friend out there, then I will fight my autism for my ability to physically put this desire into action and take the initiative to get out there and share as I wanted. When my brain misinterprets overwhelming exposure-shyness (due to the self-expression such initiative and sharing would entail) as pain and it takes this shyness-pain to be a not-want and freezes me to the spot so I can only look through a window, I will fight that faulty brain message for the want of my spirit. I will tell it mechanically how to get my feet down the stairs and out the door. I will tell it—you got it wrong. I know my want.

When I am crying inside with the need or want to share a feeling in words or face or touch, then I will fight my autism for the ability to express myself. When the stumbling awkwardness of the connections creates such frustration that my brain hears the frustration louder than the desire and calls the frustration "anxiety" and makes me "run" or "evade" or "lose all connection to my mouth or voice" then I'll fight this brain-misfire for the want in me. I'll mentally talk to it, shout at it, bargain with it but I will tell it in no uncertain terms THIS IS MY (autistic) LIFE—not the life of some broken physical-brain (not mind) mechanics.

When I am hurting and I want the hurt to stop, I will fight my autism for the want to stop it. If I am hurting myself or others by running, evading, or rambling because of misfire, then I may remove my body from the room, taking this out-of-control physical-brain (not mind) with it. Or I may close my mouth and use all my will to stop the rambling or I may rock

or tap to get my physical-brain to be less chaotic. If my brain produces chemistry that creates such a compulsiveness in following through with its misfire that it physically attacks the thing that is mechanically stopping its messages to run, evade, ramble (the spiritual "me" in my body), then I will use all my will to hold my arms and legs away from the rest of my body and if I can't fight the urge, I will tell someone to help me stop impending self abuse.

THAT is fighting my autism. It is fighting it for my own life—not the life that "the world" dictates—nor the life dictated to me by misfirings, overfirings and non-firings of a physical-brain (not mind). I am fighting it for my (autistic) spirit-emotions (mind).

CONCLUSION:

I have heard from auties who have misunderstood that section at the back of *Somebody Somewhere* about What Autism Is To Me. I have heard from others to whom it is like a prayer with which to free one's (non-autistic) spirit and to forgive oneself and one's destiny when or if one cannot get free.

What I wrote does not take away from the ownership of oneself for one is far more than a broken brain. It gives one the ownership of one's (autistic) spirit—a (autistic) spirit (mind) often confined by that physical-brain (not mind). Admittedly, it is the nature of different people's autism that some are more confined than for others.

The point is, not to fight autism per se, but to fight it *only for the right reasons* and to realize that "the world" will force-feed auties with many many wrong reasons to fight autism and no one should waste their precious effort on things that do not come from their own selfhood.

As some auties have misunderstood my What Autism Is To Me section in *Somebody Somewhere*, so too have some auties misunderstood the "proud to be an autie" stance that comes through in so many ANI articles. Some wrongly think they are being told not to fight their difficulties and they feel angry. I think that if we realize there is the (autistic) physical-brain (not mind) part of autism (which can be good or bad) and that there is also a (autistic) spiritual (mind) part of autism (which can also be good or bad), and that the two things are not the same and ARE separable (at least for some people), then people can see that "proud to be an autie" and "I will fight autism" stances are not at war with each other and can co-exist. I think it is also important to say that I do NOT have a non-autistic (nor dog, nor worm, nor tree) spirit (mind) hiding within the confines of an autistic physical-brain. I have an autistic (human) spirit within me, often confined by the limitations of an autistic physical-brain and I will fight confinement wherever I find it, whether it is at the hands of an ignorant "the world" or whether it is at the hands of a bundle of brain misfirings, no less worthy of fighting than if I had cerebral palsy or MS.

REMINDERS OF DONNA WILLIAMS IN MY APARTMENT

By Kathy Lissner-Grant

In this essay, I am going to write about what Donna Williams left behind in my apartment two years ago or sent me over the years. Whenever I look at these things, I think about her.

In the kitchen and bathroom, while she was here she labeled with my label gun many things in French and German. So my mirror in the bathroom has DER SPEIGEL and LA MIRROR on it. And so on with my door, bookshelf, thing I put my phone on, etc. I never peeled these off and now I don't want to.

When I open up the top drawer to the little table beside the kitchen table, I have a piece of cloth with sequins and a fake blue rock in it. Donna likes things like these and so she gave it to me. Whenever I see this piece of cloth, it reminds me of how she loses herself into the colors and feel of things.

In the living room, on my wall

near my maroon chair is a picture of a cat she drew from a copy of a British stamp. I love cats and this drawing shows me the many talents my dear Australian friend has. I was sent this a few years ago, and I like it so much, it's been on my wall. Also in scrapbooks of mine I have leaves from Australia that she sent me. They are still there, green. She sent me these when she lived in Australia. Also, I have in my bookshelf a copy of *Nobody Nowhere* in Japanese because that book was the #1 best seller in Japan. (Donna sent me this copy a few weeks ago because she knows how much I like things in foreign languages.)

Last, but not least, I have a tape of music that she has written and recorded. One of the songs is "Nobody Nowhere." This musical tape shows what a musical talent she is.

Donna, thanks for all the little things you have given me over the years. I really appreciate all of what you have done for me.

GUESS WHO ISN'T COMING FOR LUNCH By Jonathan Mitchell

"So, Jonathan, when are you going to get married?" innocently asks a co-worker at my new job during a St. Patrick's Day potluck.

"When I meet the right person," I reply, trying to put on a jovial facade.

Though I am making an effort not to show it, on the inside I am rather hurt and depressed by this question. You see, I have a developmental disability. I am possibly autistic or at least have autistic-like symptomatology. This has caused me to have tremendous problems in relating to people. In particular, I have problems in relating to prospective significant others. I am now 38 1/2 years old and this has caused me some grief since adolescence.

Although I have had some occasional dates, I have never been married or had a girlfriend and this is something that has caused me some psychological pain. I have dated both handicapped and nonhandicapped women. None of these women has worked out for me. In spite of the fact that the three handicapped women were the ones that went out with me more than once, they also either lost interest in me quickly or they did not work out either.

The reasons that I have never had a girlfriend are probably numerous and so complicated that I don't fully understand them myself. I have no doubt, however, that one of the factors is society's attitudes towards "mixed marriages," i.e., relationships that handicapped persons, particularly males with autism, have with nonautistic/nonhandicapped significant others.

Many persons in this society frown on my dating a nonhandicapped woman or at least feel I am incompatible with a nonhandicapped woman. Many also feel that I would be

more compatible with a handicapped woman. When I have talked to acquaintances about various "women problems," those who knew my situation would inquire as to why I could not find a nice autistic girl. Others have said that I should find someone "like myself," a polite way of telling me that I am unsuitable for a nonautistic/nonhandicapped woman.

Even some handicapped people themselves feel this way. For example, Bernie, a friend who has bipolar disorder and is married to an autistic woman, tells me about nice autistic women whom he knows and whom he feels would be good for me. Unfortunately, these women live in Baltimore, 3000 miles away from me. When I ask Bernie why a woman with autism is better for me than a nonhandicapped woman, he replies with the old saw about birds of a feather.

Professional persons who are specialists in autism seem to have these attitudes as well. I remember one encounter I had not too long ago with a research psychologist acquaintance of mine who is a specialist in autism. He asked me if I would ever like to get married and what my thoughts were on marriage. I told him that I would like to get married someday, but my standards would be high for marriage; higher than just for casual dating. If I were to marry, this person would have to be someone absolutely outstanding in my mind and someone with whom I would be compatible in a lifelong relationship. However, I felt that this type of person would never want someone like myself. So, for that reason, it was unlikely that I would ever marry.

"Does that mean you would not marry someone who is handicapped?" he asked in a tone of voice which I felt was not only perfunctory but bordered

on hostility.

I patiently explained to him that this meant nothing of the sort. Just that I wanted someone whom I was attracted to and would be compatible with in a lifelong relationship, regardless of whether or not this would be a "mixed marriage."

Another interesting instance of an autism specialist having perplexing attitudes regarding "mixed marriages" is Uta Frith's attitude towards an autistic man named David Miedzianik. Dr. Frith is a cognitive psychologist in Great Britain with a research interest in autism. She has authored a variety of books and articles about autism, including a recent one in "Scientific American." She is well known in the autism community, particularly in Great Britain.

David Miedzianik is an autistic man who also lives in Great Britain. He has written a 110-page autobiography detailing the autistic experience. A good portion of David's autobiography is devoted to bemoaning the fact that he does not have a girlfriend. David writes in his autobiography:

I think if some girl would take a real interest in me I would just bother with her and no other girl, but I spend my time talking to a lot of girls, hoping I can find one that will take a real interest.

Dr. Frith has written a book entitled *Autism: Explaining the Enigma*. In this book she quotes, or rather misquotes, from David's autobiography:

I think if some NORMAL (emphasis added) girl would take a real interest in me I would just bother with her and no other girl, but I spend my time talking to a lot of girls, hoping I can find one that will take a real interest.

I find Dr. Frith's misquote and use of the adjective "normal" to be interesting. This is something that she added to the text of David's autobiography. Nowhere in David's book does he express a preference for nonhandicapped women. I don't know whether Dr. Frith deliberately misquoted David or if this was just a careless error on her part. However, I don't believe that the use of the word "normal" was random and no doubt it reflects some perplexing attitudes that she has regarding "mixed marriages."

This is not to say that my psychologist acquaintance and Dr. Frith are out-and-out bigots, but only that they might consider re-examining some of the attitudes that they have. These attitudes undoubtedly contribute to the psychological detriment of persons in whom they have taken such a strong academic interest.

I ask Rebecca, a married friend of mine who has an autistic nephew, why society has these attitudes. She does not really seem to have a satisfactory answer to that question. I can't help thinking that she is just sparing my feelings. She does, however, give me the analogy of all the interracial couples that exist and how many people frowned on them getting married. She states that because of this, this should not stop me from being able to marry a nonhandicapped woman. I tell her that I feel that this is an apples and oranges comparison.

Then again, maybe it is not entirely apples and oranges. I think back to the 1967 movie "Guess Who's Coming To Dinner" in which Sidney Poitier plays a black man who is about to marry a white woman whom he has just met. He meets her parents and they are shocked to find out their future son-in-law is black. Likewise, when the black man's parents meet their future daughter-in-law they are equally shocked by her race. I feel that my

situation is somewhat analogous. There is a 4 to 1 ratio of autistic men to autistic women. Very few of these women would really be high-functioning enough to relate to me on my level. Of the few "eligible ones," they might be in relationships, or not interested in me, or I would never get to meet them, etc. The same is true for ladies who have other types of handicaps. This is not to say that I would object to a relationship with a handicapped woman. I certainly would not if she were someone I liked. Only that I don't feel that I should be entirely limited to dating handicapped women, who make up a fraction of the total population of eligible females, in spite of how society and so-called normal women feel.

All of these issues and the movie "Guess Who's Coming To Dinner" remind me of an incident that happened to me about six months ago. At one time, I was on the board of directors of an organization that provides a variety of services, including job coaching, to severely autistic individuals. Through my work with this organization, I met an extremely attractive lady who supervised a job coaching program in this organization. I wanted to ask her out but was never able to find the nerve or a good opportunity. Finally, partially at Rebecca's urging, I phoned her at her job and asked her if she and I could get together for lunch (an innocuous request I thought).

"Sorry, Jonathan, we are very busy here and they are not letting me out for lunch. However, you are welcome to come by and say hello to everyone here."

I had taken a tour of this organization before and had met a number of persons who had worked with this lady before.

"May I come by this week?" I asked.

"We're busy all this week, call

back on Monday."

Well, guess who isn't coming for lunch.

I called them the following Monday. I was told that she was not in the office. I called other days as well. The people who answered the phone there claimed that she was either out sick or out in the field doing something. I finally left a message for her to call me back. She never did. Obviously, she was avoiding me just because I had asked her out for lunch. I wondered what I could possibly have done that would offend her so much that she would avoid me like that. Is it just that she wanted to spare my feelings and could not deal with me after having rejected me? I suppose this is a reaction numerous women have when asked out. Is it possible that she was offended by having someone with slight autism ask her for a very casual date? I don't know the answers to these questions for sure. The incident is typical of a variety of problems I have had with the opposite sex.

I don't fully understand why I am considered unsuitable for a nonhandicapped woman. I certainly don't understand why society considers me more compatible with a handicapped woman than a nonhandicapped one since this contention certainly has not been borne out by my personal experiences.

I know these are a couple of old cliches, but I would like to say them anyway. To any lady who might happen to read this and has never had a mildly developmentally disabled significant other and is repulsed by that notion: Try us, you'll like us. To know us is to love us.

I don't know if I will ever get married or ever have a girlfriend or ever go on another date for that matter, but in the meantime, guess who isn't coming for lunch.

**CONFERENCE TIPS FOR PARENTS TAKING AUTISTIC CHILDREN
& FOR PERSONS INTERACTING WITH AUTISTIC PEOPLE**
By Katherine French

1. Do not force Autistic people to shake hands. Many Autistic people would prefer to meet others more indirectly. It is OK for them to not want to touch strangers and even people they do know. Don't worry about appearing like you've "trained your child well" so that he or she appears normal in social situations. Others can feel the limp handshake, see the eye aversion, and will feel empathic towards your child for being forced to do something uncomfortable. Wait for the Autistic person to extend her hand first if she'd like to.
2. Don't expect your child to enjoy long instructional sessions. "My Suzy will sit through anything without flapping her hands or hitting herself in the head." You have nothing to prove to the other 2000 people around you. Showing sensitivity and consideration in love will open people's eyes more than having a well-trained "poodle." Know your child's social limits and respect them. Watch for early distress behaviors and attend to what she needs to be comfortable again.
3. Suggested things to bring: ear plugs, sunglasses, and something small to hold or fiddle with. Having a small toy to work with when anxiety levels are high could help release some energy so an outburst of protest won't happen. If an outburst does happen, realize it's OK. That everyone around you is there to learn and that they understand it's a new and taxing environment for the Autistic person.
4. Your child can sense if you are not pleased with her or if you're embarrassed by her presence. Show lots of encouragement and appreciation of her in her presence. If she feels you are not happy she may try to do something to please you and the situation may become worse.
5. Autistic people are not deaf. "Well, my Suzy just hates pens. She puts them up her nose and in her ears." She can hear you give away personally embarrassing information. If what she hears for four days is horror stories about weird things she does, don't expect her to behave positively. We all like to be spoken of in a respectful manner and to have our "stories from home" left at home.
6. Bring some food she likes and that she eats regularly. Anything that looks and tastes familiar can help ease the newness of everything else. One stable factor can help her feel secure. Her favorite food could also be used to calm her down during a time of distress. We all like a little comforting. Don't be surprised if she rejects the fancy, expensive foods. She'll eat when she becomes hungry. Perhaps a quiet meal in the hotel room will help too.
7. Comfortable clothes and clothing that is familiar to your child will work best. Buying a whole new wardrobe for her so you'll feel she looks more presentable may help you feel good, but may make her feel uncomfortable, itchy and unhappy. Lace and tights may look pretty, but not if she's shed them in a room of 1000 people. Those pink sweats she wears every day may be stained and ragged, but if you'd like a peaceful, content child you may need to give a little. If you do buy a new outfit, give it plenty of use before the trip. The washing will make it soft and the texture and structure won't be so new.

MEDIA REVIEW COLUMN

by Stephen Drake

[This column is a new feature that will appear in each issue. Our reviewer is a graduate student in special education, and is also a person with developmental neurological impairments. He will write these reviews from his perspective as a researcher who is also a "cousin."

Materials to be considered for review in this column should be submitted to Stephen Drake c/o ANI. Selection of materials to be reviewed is at the discretion of the reviewer. Materials submitted for review WILL NOT BE RETURNED.)

SOMEbody SOMEWHERE, Donna Williams, Times Books, 238 pp. (ISBN: 0-8129-2287-5).

The lot of a reviewer is not an easy one (any authors out there can feel free to groan). At least the lot of this reviewer is not easy. It feels that way when one's first request from a persuasive editor is to review Donna Williams's new book, *Somebody Somewhere*. Well, no one ever said life was easy, so the following is my first attempt at writing something of this sort.

Somebody Somewhere takes us through Donna's efforts to come to terms with her autism, herself, and the world. Throughout this journey, she is at times blocked by bigotry and at others supported by real friends. She also discovers the new world of developing a "specialship" with another person.

Donna's journey depicts aspects of autism familiar to many ANI members. The frustrations of trying to adapt to a world that is designed for people whose nervous systems work differently from one's own. The appalling feeling that occurs when one thinks one's constant efforts to adapt, compensate and pass have been successful, only to find out that they have only resulted in being misinterpreted and mistreated in new ways.

Passages describing Donna's observations and work with children in special education are especially insightful and should be read by every professional in the field. Donna's interpretations of labels such as mental retardation tend to fly in the face of "professional wisdom." So do

her interpretations of behavior. And the results of her work with children are described as different from her coworkers' as well.

Donna has grown as a narrative writer. I found the style and flow of this book to be an even smoother read than her previous one. The bulk of the book chronicles a continuing journey of struggle and self-discovery.

That is why the last pages of the book felt like hitting a wall. The last pages take the form of a summary statement on what autism is. And, in this case, autism is the enemy and the other. It seems to conflict with the very complicated picture in the rest of the book.

It is unfortunate, from the perspective a self-advocacy organization, that such a piece has been presented in this way. Its placement as a closing to the book invites its interpretation as a summary statement. Moreover it is a piece ideally suited for newsletters in terms of length. I have already encountered its use by a parent to support the "autism is a curse" perspective.

That puts self-advocates in an unenviable position. On the one hand, we assert that it is important that differences and disability be defined from the inside. That we all have a role in defining who we are rather than leave the job to the professionals. On the other hand, some of us already have to argue against the generalization of the content of the final pages.

Elsewhere in this issue Donna

says the ending of her book has been misinterpreted and gives us yet another picture of how she views the experience. The letter in this issue is consistent with the tone in the main body of *Somebody Somewhere*. I find myself wishing that a form of this latest letter had been the close of her book. I have compared what Donna has written here and the final pages of her book, and I have trouble seeing where the misinterpretation is. The description included in this issue is not what was written in the book.

Having any kind of disability or difference is a complex issue. Most people that I know are constantly and continually evolving their relationship between themselves and their

differences. Not everyone ends up interpreting their relationship in the same way. Writings by people with Tourette's syndrome reveal the same kind of diversity. Some view their syndrome as something apart and others view it as integral to who they are. And that is how it should be. We are all, autistics and cousins, individuals rather than syndromes.

In the end, the issue of what any of us wishes another had written is irrelevant. The fact is, Donna has the right to interpret and define her life in any way she sees fit. Part of the lot of people who advocate empowerment and a voice for others in our community is to have to hear and deal with things that we disagree with.

In a city of lights
I am riddled with darkness
dark little people
shining black upon me
by the hundreds and thousands

they surround my loneliness
suffocating my dreams
supplanting my soul
How I wish this were a tunnel
just a simple tunnel
rather than an ocean
in which I am drowning
the light, the moon's reflection
on the surface above me
the only thing pointing, pulling me up
In abyss beyond hope
I choose yet not to drown

Iatia

DESIRABLE INVISIBILITY

By Geneva Wulf

I have just reread Mr. Sternberg's article on (undesirable) invisibility. My response is, yes, I know about the *unwelcome*, *uninvited*, and *undesirable* types of invisibility. But do you know about the *welcome* (wish I could), *invited* (often) and *desirable* type?

It comes up like this: I walk into a room, and there on the other side of the room is "that" person. It is the one that it always judging everyone, and accusing them of having motives that they never even thought of. She talks about everyone. Oh great! Now she's looking at me and grinning...AND talking to "them".... If I could only get my hands on some invisibility spray... I could go "Poof" and I would slowly begin to fade, until I was INVISIBLE.



Then I would walk right up in front of her, and AT LAST... I would know what people really think about me. I would know what they are saying.

Of course I know that the various forms (uses) of invisibility are not

ours to manipulate. Rats!

People can't "wish" me into non-existence.

I can't walk around unseen, even if it is to uncover clues that would help me to define myself.

Oh—I know of one more form: "Projectable invisibility." If I could get my hands on some... well... I do threaten, even now. Someone goes somewhere, and I wish I could see what they're going to do. (Like on a date.) So I tell them I'm sending "Fred" along to keep an eye on them. "Fred" is my (invisible) pet fly. He can land on the wall and watch and listen, and report back to me what he's found out.

NO ONE suspects a fly... right? Right!

"Ho Ho"
"Tee Hee"

Just think of all the fun I could have. And how much I could learn about how to act in new and unfamiliar circumstances.

Like I said to start with, do you know about desirable invisibility? You do now.



FROM THE EDITOR'S MAILBOX
by Jim Sinclair

[From time to time I receive letters that are not submitted for publication, but I think the issues raised would be of interest to members of ANI. When this happens I may print my own responses in this section. The identity of people who write to me privately will NOT be revealed, only those portions of my replies which are of general interest and do not reveal personally identifying information about the individuals who sent the letters I am replying to.]

When sending letters, poems, or other materials to me, please be sure to specify whether they are FOR PUBLICATION or PRIVATE. Please do not submit for publication materials that were written by someone other than yourself, unless accompanied by a statement that the person who wrote the material has consented to having it published. And finally, please understand that while I would like to be able to send a personal reply to everyone who writes to me, it isn't possible for me to do that. If you have a issue you would like to raise for discussion, consider sending a letter FOR PUBLICATION. That way, if I am not able to respond to it myself, maybe someone else will see it and respond to it.]

The questions I am responding to in this column were sent by someone who asked:

How do you know the difference between a thought and a feeling? I have lots of thoughts in my head, but where do you find a feeling? Is a feeling like happy or sad the same kind of feeling as a nail that pokes you, or something that feels hot or cold on your hand, or when your stomach feels sick? My uncle said when your stomach feels sick, and it's not from eating too much food, that could be a scared feeling.

Those are very interesting questions! I've done a lot of thinking about defining emotion when watching Star Trek episodes about Data and his supposed lack of emotions, and my own memories of learning to communicate about feelings are still fairly recent, so I'll see what I can do with these questions.

First of all, I think "feeling" is an ambiguous word because non-autistic people use it to mean so many different things, because they can usually understand each other well

enough to know which meaning is intended so they don't even notice it's ambiguous.

One meaning of the word "feeling" does refer to physical sensations in the body that can be felt the way tactile sensations or an upset stomach can be felt. These sensations are things like breathing hard, fast heartbeat, sweating, flushing, laughing, crying, trembling, goose bumps, and a lot of feelings in the viscera, such as clenching (from muscles tightening) or fluttery sensations (caused by blood rushing in and out of the visceral organs). Those are all physical reactions that can come from emotions.

But they're not emotions all by themselves; they can also come from other things. For example, breathing hard, a fast heartbeat, and sweating can also come from exercising, not from emotion. Shivering and goose bumps can come from being cold, not from emotion. Sweating and flushing can come from being hot, not from emotion. Tears in the eyes can come from eye irritation. Fluttery feelings in the stomach can come from having low blood pressure. All those physical responses just mean the body is reacting to something. The physical part alone doesn't tell you

what the something is.

Also, a lot of the time my body doesn't react very strongly, or doesn't react at all, to my emotions. Some people have tried to tell me that this means I don't have feelings. I think that's nonsense.

I think the most important part of emotions isn't the physical sensation part, it's the *meaning* part. A thought is one sort of meaning. When you think about things that are just plain facts, and you don't have any sense that the facts are good or bad, only that they're true, that's one kind of meaning. But when you think about something and the thing you think takes on a personal meaning for you, I would call that the basis of emotion. Or when you perceive something, even without thinking, and the thing you perceive has a personal meaning, that's also the basis of emotion.

Here's an example: Suppose I look out the window and I see someone coming up the walk. That's a perception. Then I think to myself, "There's someone coming." That's a thought. I might also perceive and think any number of things about who the person is, where the person came from, what the person looks like, what kind of car the person arrived in, etc. Those are all thoughts. I might be thinking, "That person has a new Chevrolet." But I'm just making a mental *observation* about the car; I don't really care, on a personal level, about the car. If it were an old Ford, I wouldn't think that was any better or worse than a new Chevrolet. My observation would be different, but my feeling wouldn't be. (This observation might be very personally meaningful to someone who had a car fixation, but since I am pretty indifferent to cars, the example works for me as something I can observe without really caring about it.)

But if there's something I do care about, then I don't just think, "This is what is happening." I also have an awareness that what is happening means something that's good or bad. There are many different

things it could mean. Different personal meanings go with different feelings. Just to give a few possibilities with this example:

Maybe I recognize the person coming up the walk, and it's someone I like and enjoy spending time with. When I see the person, I know that it's a good thing for me that this person is here. It means I'm going to get to spend time with someone I enjoy being with. This knowing that something good is happening is being happy.

Maybe I recognize the person, and it's someone I don't like being with. When I see the person, I know that I'm about to have an experience I won't like (having to spend time with someone I don't like). Knowing that something bad is happening is being unhappy.

Maybe I think that the person is going to do something very bad. I want to escape, or to make the person go away. It's hard for me to focus my attention on anything else, because I keep thinking that something bad is going to happen. That's being afraid.

Maybe the person is someone I didn't expect to see, because I thought this person was far away. When I see the person, I know that what I thought must not be the case, and my mind very quickly starts to reorganize what it believes to fit this new information. That's being surprised.

There are other possible feelings too. The important difference is that while observations and thoughts are neutral, feelings are what the observations and thoughts mean to you. Feelings are what motivate you to want to do something about the thing you're thinking: If something makes you happy you want to experience more of it; if it makes you sad or afraid or angry you want to avoid it or change it. If something moves you to decide that it's a good thing or a bad thing, and to want to do something in response to it, then that's some kind of emotion. (The words "emotion," "motion," and "motivation" all come from the same root.)

All the physical reactions the

body may have are just ways to get ready to do something. I think the really important part is the experience of personal meaning and being inspired to take action, not the glands squirting hormones. (This is why I think Data does have emotions, even though he doesn't have glands or hormones. He has things that are important to him, and he sets his priorities and chooses his actions based on what he personally experiences as important.)

For most people, the experience of meaning and the squirting of hormones and the expressions that other people can see all go together. For autistic people that might not happen, so it's harder to learn which words go with which feelings. For that it really helps to have a helpful (and patient) person who's willing to explain things in a lot of detail. I didn't meet someone like that until I was about 25. Then I had a very wonderful friend named Kiesa who taught me most of the feeling words I know today. She would tell me a lot about how she was feeling all the time.

She wouldn't just tell me the name of the feeling. She would also tell me what sensations the feeling caused in her body, and what signs I could see in her face or her voice or her body language to recognize the feeling, and what had happened to cause her to feel that way. If I still didn't understand what the feeling meant, she would explain even more. The way I learned to understand was to ask questions that let me translate her feeling words into idea structures.

For example, she might tell me that she was frustrated. I asked why she was frustrated. She would tell me some facts about something that happened at work. I would ask what it meant that this thing happened. She would explain more about how things got done at work. Finally, by asking a lot of questions, I would find out that she

thought the thing that happened at work was a wrong thing, and that she had been trying to get things to change so it would be different, but the other people she worked with didn't listen to her. So I learned that frustration means wanting to do something (like change something that seems wrong) but not being able to (because other people won't listen). We had many many more discussions like that.

Another thing Kiesa did was to ask me questions about my feelings. At first I didn't understand the questions, so I had to ask more questions about what the words meant. In those discussions I would start by telling her what I was thinking. I might tell her about something that happened at my job, and what I thought that thing meant. Then she would ask if I felt angry about that. So I might ask her the difference between angry and frustrated, or discouraged, or other feelings I wasn't sure about. From a lot of individual instances of figuring out which word fit what I was feeling in that specific situation, I learned to recognize which word to use to describe my feelings in new situations. It took a long time and a lot of long discussions.

Everyone has a different understanding of some of the meanings of feeling words, and everyone has unique personal ways of experiencing and expressing emotions. Learning how to discuss feelings with Kiesa gave me a start on a vocabulary, but it still doesn't tell me how to know what other people are feeling. But since I now know some words to use in asking questions, I can learn about other people's feelings a little more quickly than I learned about Kiesa's. It's still important to have people who are able to explain what they're experiencing. If people can't describe their feelings, or if they get impatient with me for asking them questions, then I still have a lot of trouble communicating about feelings.

SOME NOTES FROM THE EDITOR

1. Publishing of "Our Voice" is irregular. I hope it will become more regular when I've finished moving and have some help running the ANI office. Until then, I cannot and will not make any promises concerning a schedule of publication. The only thing I can guarantee is that if you pay for a one-year subscription, you will receive at least four issues (more if we can fit them in) for your subscription fee, however long it takes for four issues to come out. Thank you for your patience and understanding.

2. Several people have asked about the buttons ANI sells at conferences. After the new ANI office in Syracuse is organized, these buttons will be available by mail. I am not taking orders for buttons now, because I don't want people to have to wait as long for orders to be filled as some of you have had to wait for subscriptions to be entered.

Autism Network International

Subscription Form

Name _____ Birthdate _____

Address _____

City, State, ZIP _____

Phone number _____

Interests _____

Circle one: AUTISTIC PERSON FAMILY MEMBER _____
(Relationship)

TEACHER _____ OTHER _____
(Age and level of students)

____ 1994 subscription ____ 1993 back issues

Enclose subscription fee of \$15 per year (\$20 overseas) and return to
ANI, P.O. Box 448, Syracuse, New York 13210-0448.

For autistic people only:

Do you want your name included in the directory? ____ Yes ____ No

Do you want your address included in the directory? ____ Yes ____ No

Do you want your birthdate included in the directory? ____ Yes ____ No

Do you want your interests included in the directory? ____ Yes ____ No

Do you have a computer and a modem? ____ Yes ____ No

If so, do you have an electronic mail address? _____

Do you want to receive a copy of the directory? If so, please read and
sign the following statement:

I am an autistic person, and I wish to receive a copy of the ANI
directory. I agree not to share my copy of the directory with
anyone. I agree not to give out information about anyone listed in
the directory unless that person gives me permission to do so.

Signature _____

"Our Voice" is a publication of
Autism Network International
P.O. Box 448
Syracuse, NY 13210-0448

Permission is given to copy and share
this newsletter, with proper credit to
ANI and the authors.